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Age and gender related differences in emotional and behavioural problems and autistic features in children and adolescents with Down syndrome: A survey-based study of 674 individuals

Abstract

Background. Recent studies have indicated an increased risk of autism, behavioural and emotional problems and Attention-Deficit/Hyperactivity Disorder in individuals with Down syndrome.

Method: In a large scale survey-based study we examined the rates of these problems, and their relationship to age and gender, in a sample of 674 individuals (4-18 years) with Down syndrome. The relationship with IQ level was also explored in a subsample (n=175). The Strengths and Difficulties Questionnaire (SDQ) and the Social Communication Questionnaire (SCQ) was used to assess behavioural and emotional problems and autism traits.

Results: On the SDQ, Peer problems were the most frequently reported difficulty (48% > cut-off), followed by Hyperactivity/Inattention (34% >cut-off). On the SCQ, 37% scored at or above cut-off (≥ 15) for autism spectrum disorder; 17% were at or above the suggested cut-off (≥ 22) for autism. Little association between age and behavioural or emotional problems or with severity of autistic symptomatology was found. However, Peer problems were more common in adolescents than in junior school children ($p < 0.001$); Hyperactivity/Inattention was less prevalent among adolescents ($p < 0.001$).

Conclusions High rates of autistic features, emotional and behavioural problems are documented. These problems are related to age, gender and degree of ID.

Keywords

Down syndrome, age related changes, Autistic features, behavioural problems

Introduction

Relative to their typically developing peers, children with intellectual disabilities (ID) are at increased risk of behavioural, emotional and psychiatric problems (Einfeld et al., 2010a; Einfeld et al., 2006). However, types and rates of psychopathology vary with different genetic aetiologies and with age, gender and severity of intellectual impairment (Davies and Oliver, 2013; Einfeld et al., 2010b; Rice et al., 2015). Although reported to show fewer emotional and behavioural problems than found in many other genetic disorders (Daunhauer and Fidler, 2011; Dykens, 2007; Fidler and Daunhauer, 2011), children with Down syndrome nevertheless typically exhibit a range of difficulties. These include “stubbornness”, attention seeking, inattention and impulsivity (Dykens, 2007); impaired concentration and poor task persistence (Fidler, 2005), and bedtime and sleeping problems (Carter et al., 2009). Attention-Deficit/ Hyperactivity Disorders are also relatively common although reported rates vary from around 6% to 8% (Dykens, (2007) to 44% (Ekstein et al. (2011). Recently, too, there has been a number of studies indicating that many children with Down syndrome meet criteria for autism spectrum disorder (ASD); however, again, estimates vary from 5% to 39% (Channell et al., 2015; Warner et al., 2014).

Differential diagnosis of conditions such as ASD or ADHD in children with moderate to severe intellectual impairments clearly presents a challenge to clinicians because of symptom overlap and the very limited communication, cognitive and social skills of many such children. Diagnosis of co-occurring conditions may also depend on the age of the child. For example, the diagnosis of autism in children with Down syndrome is often made at a relatively late age (Rasmussen et al., 2001). In typically developing children, disorders associated with externalising behaviours tend to decrease over time whereas disruptive behaviours, such as aggression, may increase with age in some individuals with intellectual disability (Davies and Oliver, 2013). Trajectories of change also vary according to the genetic condition involved. Thus, Rice et al. (2015) found that physical aggression and tantrums decreased between childhood and adolescence in individuals with Down syndrome, Fragile X and Williams syndrome but not in Prader Willi syndrome.

Gender, too, is an important factor. Disorders such as ASD and ADHD are consistently reported to be more prevalent in boys than in girls, with an average male: female ratio of around 2:1 for ADHD (Ramtekkar et al., 2010) and 4:1 for ASD (Baird et al., 2006). In ADHD the M:F ratio ranges from 3:1 in epidemiological studies to 9:1 in clinical samples and patterns of symptomatology vary between males and female with less primary symptoms and externalising behaviour in females (Gershon, 2002); clinically diagnosed females also tend to be of lower IQ (Baker et al., 2010; Gershon, 2002). In autism, the gender difference among individuals of higher IQ is approximately 8-9M: 1F, while in groups with intellectual impairment the ratio is closer to 2:1

(Halladay et al., 2015; Mandy et al., 2012). Patterns of autism symptomatology also tend to differ by gender, with less repetitive and externalising behaviour and more emotional problems among females (Halladay et al., 2015; Mandy et al., 2012)

The main aim of the present study was to explore age and gender related rates of emotional and behavioural difficulties and autistic symptomatology in a large sample of children with Down syndrome. On the basis of existing research, it was predicated that rates of both behavioural problems and autism symptoms would be high but the specific research questions were: (i) do children with Down syndrome show age related patterns of behavioural difficulties and/or autism symptoms? (ii) are gender differences in patterns of behaviour problems and autistic symptoms similar to those found in non-Down syndrome groups? (iii) (in a subsample only) is severity of behavioural and/ autism symptoms associated with level of intellectual disability (ID)

Method

Participants

Children were recruited from two related survey studies, one conducted in the UK (Warner et al., 2014) the other in Norway, which were part of a wider Scandinavian/UK study of trajectories of development in Down Syndrome. As the Norwegian and UK participants had completed the same behavioural measures the cohorts were combined to increase statistical power. Additionally, in the Norwegian sample, data on IQ levels were available, allowing examination of the relationship between problem areas and estimated levels of intellectual disability (ID).

UK cohort: Families of children (age 6-15 years) with a diagnosis of Down syndrome living in England and Wales were recruited via the UK Down's Syndrome Association and asked to take part in a study of differences among children with Down syndrome. In total, 1382 families were contacted; 507 (36.7%) questionnaires were returned but eight (1.6%) were incomplete resulting in a sample of 499 participants

Norwegian cohort: Families of children aged 4-18 years were recruited via the Norwegian Down Syndrome association. A total of 421 families was contacted; 175 (41.6%) returned completed questionnaires. The overall response rate was 37%.

Table 1 about here

The total cohort comprised 674 individuals. Boys slightly outnumbered girls in both samples (59% in Norway and 56% in UK); mean age was 10.5 years ($SD = 3.1$); ($M = 10.8$ years; $SD = 3.9$ in Norway; $M = 10.4$ years;

SD 2.8 in UK). There was no significant difference in age or in the proportion of males in the two cohorts. Children were divided into five age groups each of three year intervals, roughly equivalent to pre-school/reception class, infant school, junior school, early high school and later high school stages (see Table 1).

Measures

Behavioural and emotional difficulties: the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997).

The SDQ is a 25-item questionnaire that screens for the presence of hyperactivity, emotional symptoms, conduct problems and peer problems in children aged 4 to 17 years. The SDQ is widely used, is available in several languages and has good psychometric properties for identifying children with behavioural and emotional difficulties in clinical and community populations (Goodman, 2001; Stone et al., 2010). SDQ scores are banded into three categories: “Normal”, “Borderline” and “Abnormal” (i.e. substantial risk of clinically significant problems). In this study scores for the “abnormal” category were used to define abnormality each domain (Emotional problems 5-10; Conduct problems 4-10; Hyperactivity/ Inattention 7-10; Peer problems 4-10).

Autism symptoms: The Lifetime version of the Social Communication Questionnaire (SCQ; (Rutter et al., 2003).

This is a 40-item questionnaire used to screen for symptoms associated with ASD: reciprocal social interaction, communication and restricted, repetitive and stereotyped behaviour. Item level validity is good (Berument et al., 1999; Bolte et al., 2008); sensitivity and specificity in school-aged samples are relatively high; .86 and .78 respectively (Charman et al., 2007; Magyar et al., 2012). Chandler et al. (2007) reported specificity and sensitivity $>.80$, together with good convergent and discriminant validity, in a large sample ($n>400$) of children with DS. The suggested cut-offs are ≥ 22 for autism and ≥ 15 for ASD.

Intellectual level

The UK survey study did not have ethical permission to ask parents about the IQ of their child. Thus, data on degree of intellectual impairment was obtained only in Norway. In that sample 106 parents reported on their child's level of ID, as based on a formal cognitive assessment; 69 parents did not provide this information.

Statistics

Associations between measures and proportional data were analysed using nonparametric statistics (Spearman's rho; Chi square test for proportions); parametric statistics (ANOVA with post hoc tests and t-test) were used when appropriate. Due to multiple comparisons, significance level was set to $p < 0.01$.

Results

Comparisons between UK and Norwegian samples.

Table 2 about here

To ensure that the two samples showed similar patterns of scores overall, profiles of behaviour on the SDQ and SCQ were compared prior to the main data analysis. On the SCQ there were no significant group differences in mean scores between the UK and Norwegian cohorts, either for the total samples or across the different age bands. On the SDQ the UK cohort scored slightly higher than the Norwegian cohort overall (See Table 2). The main difference was for Age Group 3 (junior school) where Conduct problems and total SDQ were higher in the UK compared to Norway (both $p=0.009$). Otherwise, profiles of behavioural and social problems were similar. The results reported below apply to the whole sample; however, if data for one or other cohort differed from the overall findings these are indicated.

Tables 3 & 4 about here.

Table 3 summarises SDQ and SCQ scores for the different age bands. Table 4 shows the proportions in each age group scoring above cut-off on the SCQ and each domain of the SDQ. On the SDQ, Peer problems were rated as the most commonly occurring difficulty, with 48% scoring above cut-off on this domain. The second most common area of difficulty was Hyperactivity/Inattention (34%); 19% scored above cut-off for Conduct problems and 14% for Emotional problems.

On the SCQ, 37% of the sample scored at or above the ASD cut-off of 15; 17% were at or above the suggested cut-off for autism (score ≥ 22). We also examined the profile of social, communicational and repetitive behaviours in these children by examining the proportion of items rated positively in each SCQ domain. Overall, approximately 30% of items were scored positively in each domain (33% Repetitive behaviours; 31% Communication problems; 31% Social problems)

Associations with age.

On the SDQ there was an effect of age on the Hyperactivity/Inattention scale (see Table 3) with hyperactivity and attention problems tending to be higher in younger children. Peer problems, in contrast, were more common in older participants. Post hoc tests indicated that the main difference was between 7-9 year olds and those aged ≥ 13 , with the former group having significantly fewer Peer difficulties but significantly more Hyperactivity/Inattention problems. Correlational data for the total cohort also confirmed that SDQ Hyperactivity/Inattention scores were significantly negatively associated with age, although the size of the correlation was small ($\rho = -0.18$; $p < 0.001$). Scores for Peer problems were positively correlated with age although, again, the size of the correlation was small ($\rho = 0.24$; $p < 0.001$). The greatest age difference was for

Hyperactivity/Inattention problems, which were not reported for any children in the 16-18-year-old group but occurred in 31% to 44% of children aged 12 or under. Correlations between age and Emotional problems ($\rho=0.09$; $p=0.02$) and Conduct problems ($\rho=-0.04$ $p=0.34$) were small and non-significant (i.e. $p>0.01$).

On the SCQ, except for a small positive correlation with the Communication domain score ($\rho=0.14$ $p<0.001$), there were no other associations with age.

Associations with gender.

Table 5 about here

On the SDQ there were no gender differences in total scores (See Table 5) although girls scored higher on Emotional problems. The proportion of girls scoring above cut-off for Emotional problems was also higher (19.4% vs 9.5%; of boys; $\chi^2 13.6$ $p<0.001$). There were no significant gender differences on any other SDQ subdomains

On the SCQ boys had a significantly higher score than girls (see Table 5.) and were more likely to score above the SCQ cut offs for ASD and autism (Males 45.1% vs Females 28.3% ≥ 15 ; $\chi^2 14.3$; Males 22.1% vs Females 9.4% ≥ 22 ; $\chi^2 13.9$ p 's <0.001). Male: female ratios (SCQ ≥ 15) were similar in the individual cohorts (UK M 45.1%; F 28.3%; 14.3 χ^2 $p<0.001$. Norway M 40.4%; F 28.1%; 2.5 χ^2 $p=0.079$) although the difference was marginal in the Norwegian sample.

There were some gender differences, too, in ASD profiles. Girls more often scored above cut-off on the SCQ Communication items (29%) than on Repetitive behaviours (26%) or Social problems (26%) while boys tended to have more repetitive behaviours (Repetitive behaviours 37 %; Communication problems 33%; Social problems 34%).

Associations with intellectual level.

Table 6 about here

Information about degree of intellectual disability (ID) was obtained from Norwegian respondents only (N=106). Of these, 25 children (25%) were reported to have a diagnosis of mild ID; 59 (56%) had a diagnosis of moderate ID; 22 (21%) were reported to have a diagnosis of severe ID.

Degree of intellectual disability was significantly correlated with scores for Hyperactivity/Inattention and Peer problems (ρ 's=0.47; 0.38 respectively; both p values <0.001). There was also a significant correlation

with SCQ scores ($\rho=0.55$; $p < 0.001$; i.e. more severe ID = more autism symptoms). Table 6 shows the percentage within each IQ group scoring above cut-off on each domain.

Discussion

This survey study of 647 children with Down syndrome, aged 4 to 18 years revealed few age related patterns of behavioural and emotional problems or autism symptomatology. The one problem area that was markedly less prevalent among older children and adolescents was Hyperactivity/Inattention. Stores et al. (1998) also found that hyperactivity scores on the Aberrant Behaviour Checklist (Aman et al., 1985) were lower in older teen-age groups than in younger children, both among participants with Down syndrome ($N=91$) and other children with intellectual disability. ($N=71$). In contrast, Dykens et al. (2002) using the Child Behavior Checklist (CBCL; (Achenbach, 1991), in a study of 211 children with Down syndrome aged 4 to 19 years found no relation between age and the subdomain of Attention problem. Dykens et al. also reported an association between age and externalising problems such as Aggression and Delinquent behaviour, whereas in the present study the relationship between age and Conduct problems failed to reach statistical significance.

The differences between our study and that of Dykens et al. (2002) are likely due to differences in samples and measures used. Thus, in Dykens' sample, 15% of participants were attending a specialised psychiatric clinic and problems in this clinical subgroup were significantly elevated. The CBCL, used by Dykens, and the SDQ, used here, also include different behaviours, and while Dykens did not find a relation between age and the Attention problem subdomain as a whole, specific items such as "Cannot concentrate" showed significant age effects. There were also several items within the Conduct problems domain of the CBCL that did not show age effects in the Dykens sample (i.e. Temper/Tantrums, Steals and Lies).

The other domain, in which an age effect was found, although the size of the association was small, was peer problems. Dykens et al. (2002) also found that social problems were more prevalent among older children, with 66% of adolescents described as preferring to be alone than with their peers. This figure is very similar to our findings of 62%-63% of 13-18 years olds having difficulties in peer relationships. Hodapp et al. (2003) also reported that adolescents with Down Syndrome were rated by their mothers as less sociable than younger children. However, it is not possible to determine, from these data, whether the apparent rise in peer problems with age is due to a decline in social skills in older children or whether the problems are primarily due to their inability to keep pace with the increasing complexity of social interactions required of older children and adolescents.

With respect to gender differences on the SDQ, although studies of ADHD symptoms in community samples generally report much higher rates of these problems in boys (e.g. (Arnett et al., 2015) we found no difference in the proportions of males or females scoring above cut-off for Hyperactivity/ Inattention. Ekstein et al (2011) also reported no association between gender and ADHD in their Down syndrome sample. On the SCQ, our finding that significantly more boys than girls scored above the cut-offs for ASD/ autism is one of the most consistent findings in autism research generally (Halladay et al., 2015). Nevertheless, the 2:1 proportion of males to females scoring at or above the ASD cut-off was much lower than the more typical 4M:1F ratio (Halladay et al., 2015).

Although data on intellectual level were only available for the Norwegian cohort and were derived from parental reports, rather than direct assessments, there were significant correlations between IQ ratings and scores for autism symptoms and SDQ scores for Hyperactivity/Attention and Peer problems; the size of these correlations was also much higher than the correlations with age. It is unclear why these SDQ findings are in contrast to those of Ekstein et al. (2011) who found no correlation between ADHD symptoms and level of intellectual disability, but this discrepancy may be due to the relatively small sample in the Ekstein study (N=36).

It has previously been reported that individuals with Down syndrome have a different profile of ASD type problems than found among ASD only samples (Warner et al., 2014; Hepburn et al., 2008). In particular, individuals with Down syndrome and co-morbid ASD appear less likely than those with ASD alone to show impairments in reciprocal social interactions (Warner et al., 2014). However, when we compared the proportion of problem items on each of the three SCQ domains, each domain appeared to contribute equally to the total SCQ score.

Study limitations

There were several limitations to this study: (i) Data were cross sectional and only longitudinal data can indicate patterns of change over time. (ii) Assessments of symptoms of hyperactivity/ inattention and ASD made using brief instruments such as the SDQ and SCQ are very different to formal clinical assessment of these disorders. Thus, we do not know if children meeting cut-offs on these instruments would meet diagnostic criteria based on more complex measures and expert clinical assessment. Furthermore, data on autism symptoms were obtained via the “Life-time version” of the SCQ which may have minimised differences between age groups. However, as the “Current version” covers only the last three months we considered that this would be too restrictive and also more difficult for parents to rate with accuracy. (iii) Although sample size is large compared with many other

studies of children with Down syndrome, data are based on survey findings which are prone to a number of biases (Robson and McCartan, 2015). (iv) Response rates, as in most surveys of this kind, were relatively low, and the fact that parents were all volunteers belonging to parent support groups introduces additional biases related to social class and culture etc. (v) There were some differences in the scores of the Norwegian and UK cohorts; however, these were generally small and applied primarily to the age groups; otherwise total scores, and patterns of scores in the two cohorts were similar, suggesting that the main findings are robust. (vi) Information on intellectual level was available only for the Norwegian participants and came from parental reports although the estimates were likely based on previous formal assessments.

Clinical implications

Despite the limitations of the study, the results confirm previous findings of relatively high rates of symptoms of hyperactivity/inattention; peer-related problems and autistic-type features among children with Down syndrome and these may well increase the burden on families. Although, as in the general population (Faraone et al., 2006) problems related to hyperactivity/inattention were less amongst older children and adolescents, peer related difficulties were significantly higher among older participants, possibly due to the increased social demands made of adolescents, rather than an actual decline in social skills. Whatever the reasons, it is important that clinicians, educators and other service providers are aware of these symptoms, and the changes in patterns of difficulties over time, when planning interventions. Finally, SCQ data suggest that symptoms associated with ASD can occur in children with Down syndrome at all ages. While assessments based on brief questionnaires cannot be used to determine the prevalence of autism amongst this group, the findings suggest that children who meet criteria on parent report measures should be referred for full clinical assessment as the additional presence of ASD has implications for both clinical and educational interventions.

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Conflict of interest

The authors have no conflict to declare

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TABLES:**Table 1. Number of participants and mean age (years) within each age group.**

	<i>N (from UK)</i>	Mean age (SD)	% Boys
Age Group 1: 4-6 years	58 (24)	5.6 (0.6)	52
Age Group 2: 7-9 years	222 (186)	7.9 (0.8)	61
Age Group 3: 10-12 years	180 (144)	11.0 (0.8)	59
Age Group 4: 13-15 years	189 (145)	13.9 (0.8)	58
Age Group 5: 16-19 years	24 (0)	16.6 (0.8)	63

Table 2. SDQ and SCQ scores for the whole sample and UK and Norwegian cohorts

	Total sample (n=674)	UK sample (n=499)	Norway sample (n=175)	
	Mean (SD) [range]	Mean (SD) [range]	Mean (SD) [range]	Mean Diff UK-N
SDQ Emotional	2.2 (2.1) [0-10]	2.3 (2.1) [0-10]	2.0 (2.1) [0-10]	0.3
SDQ Conduct	2.2(1.8) [0-8]	2.3 (1.8) [0-8]	1.7 (1.6) [0-7]	0.6*
SDQ Hyperactivity	5.4 (2.5) [0-10]	5.6 (2.5) [0-10]	4.5 (2.6) [0-10]	1.1*
SDQ Peer Problems	3.6 (2.2) [0-10]	3.5 (2.1) [0-10]	3.8 (2.2) [0-9]	- 0.3
SDQ Total	13.3(5.9) [2-36]	13.7 (5.9) [2-36]	12.2 (6.0) [2-31]	1.6*
SCQ Total	13.0 (7.9) [0-36]	13.1 (7.7) [0-36]	12.6 (8.5) [1-33]	0.5

* $p < 0.001$

Table 3. SDQ and SCQ scores across age groups.

	Age Groups						
	(1)	(2)	(3)	(4)	(5)		
	4-6 years (n=59)	7-9 years (n=222)	10-12 years (n=180)	13-15 years (n=189)	16-18 years (n=24)		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	F value	Post hoc
SDQ Emotional	1.7 (1.9)	2.1 (2.0)	2.3 (2.1)	2.4 (2.3)	2.5 (1.9)	1.48	
SDQ Conduct	1.6 (1.2)	2.4 (1.8)	2.1 (1.7)	2.1 (1.9)	2.2 (1.8)	2.96	
SDQ Hyperactivity	5.3 (2.4)	6.0 (2.5)	5.4 (2.4)	4.8 (2.4)	3.7 (1.9)	7.98**	2>4, 5
SDQ Peer Problems	3.2 (2.4)	3.0 (2.1)	3.7 (2.1)	4.1 (2.1)	4.6 (2.2)	9.91**	4, 5>2
SDQ Total	11.8 (5.9)	13.5 (6.1)	13.5 (5.8)	13.3 (6.1)	13.0 (6.1)	1.09	
SCQ Total	11.0 (8.8)	12.8 (7.6)	13.0 (7.9)	14.1 (8.2)	11.8 (7.6)	1.77	

*p <0.01

**p <0.001

Table 4. Percentages for each age group who score > cut off on SDQ sub domains and SCQ

	Total	Age Groups				
		(1)	(2)	(3)	(4)	(5)
		4-6 years	7-9 years	10-12 years	13-15 years	16-18 years
SDQ Emotional Problems	14%	7%	12%	16%	17%	8%
SDQ Conduct Problems	19%	7%	23%	20%	16%	21%
SDQ Hyperactivity	34%	31%	44%	33%	27%	0%
SDQ Peer Problems	48%	41%	36%	48%	62%	63%
SCQ >15	37%	28%	35%	34%	45%	50%
SCQ >22	17%	17%	15%	17%	21%	8%

Table 5. Gender differences on SDQ and SCQ			
	Girls (n=287-289)	Boys (n=374-380)	Sig difference
SDQ Total	13.3	13.3	
SDQ Emotional Problems	2.6	1.9	t =3.8; p <0.001
SDQ Conduct Problems	2.3	2.1	
SDQ Hyperactivity	5.1	5.5	
SDQ Peer Problems	3.6	3.6	
SCQ Total	11.2	14.3	t =5.0; p <0.001

Table 6. Proportion scoring above cut off on SDQ and SCQ x degree of ID

	Severe ID	Moderate ID	Mild ID
	n=22	n=59	n=25
SDQ Emotional Problems	5%	15%	4%
SDQ Conduct Problems	9%	14%	8%
SDQ Hyperactivity	68%	20%	4%
SDQ Peer Problems	82%	44%	44%
SCQ > 15	91%	34%	21%
SCQ > 22	68%	15%	4%